Living with Rheumatoid Arthritis

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CHAPTER 1

General introduction

1.1 Background

This thesis focuses on the relationships between selected personal and social resources as well as Health Related Quality of Life (HRQoL) when facing the burden of rheumatoid arthritis (RA). The emphasis is put on social and psychological factors which have been shown to play an important role throughout the disability process in previous research [1-4]. Due to the problem of a lack of direct correspondence between the objective disease activity assessment and the subjective perceptions of the patients concerning the impact of RA on their lives, this is a highly relevant issue in this context [3-5]. Both subjective and objective assessments of the disease severity and its impact on patients´ lives require special attention in research and practice. This is especially in respect to functional disability and activity restrictions which may further impede psychological and social functioning of the patients and thus affects their overall HRQoL and hinder social participation.

The research questions of the thesis address issues regarding specific personal and social resources in the studied patient group and explore especially how they relate to aspects of psychological distress and other aspects of HRQoL. Applied methods include both longitudinal and cross-sectional research designs allowing for analyses at different points of the disease duration. The cross-sectional analyses provide information about associations between variables and the longitudinal analysis is used to analyze changes within a specific time period as well as to provide prospective associations enabling to in some extent inference on causal relations. This first chapter provides an introductory overview of RA with anemphasis on psychological and social impact of the disease on individual patients. The relevance of social and psychological resources of the patients is argued and discussed in the conceptual framework of International Classification of Functioning Disability and Health (ICF) [1]. The chapter concludes with stating the research questions within and the structure of this thesis.

1.2 Characteristics of rheumatoid arthritis

Rheumatoid Arthritis (RA) is a chronic progressive autoimmune disease which is characterized by systemic attacks of immune cells on the synovial tissue of the joints [2]. These attacks cause typical swelling and tenderness.

As the disease progresses the cartilage, bone and ligaments become eroded and may result in a significant impairment or even a complete loss of function of the joint. This process is connected with experiencing pain, stiffness, fatigue, and leads to formation of visually noticeable deformities and physical impairment typically demonstrated by overall decreased functional status [3].

The prevalence of RA is about one per cent worldwide and the disease is more common in women than men with a ratio of approximately 3:1. The peak onset usually occurs in the fifth decade of life. Up until recently, the diagnostic criteria for Rheumatoid arthritis were based on the criteria of the American College of Rheumatology published in 1987 [45]. However, due to criticism of their lack in sensitivity new criteria were issued and approved by both ACR and the European League Against Rheumatism (EULAR). Diagnostic criteria embraced in this study adhere to the ACR criteria as the majority of the data were collected before 2010.

Psychological manifestations may often be characterized by feelings of hopelessness, loss of control and significant uncertainty about the future course of the disease and how it affects future life and its quality [4,5,6]. This predisposes RA patients to increasing levels of psychological distress and especially to depression, anxiety and a negative perception of self. The interplay between clinical impact and poor psychological adaptation has been described as a potential risk for future maladjustment to the disease as it might result in a self-reinforcing loop also coined as vicious cycles [7,8,9].

Repeated findings of diminished HRQoL among RA patients can be understood as a result of the vicious cycles. Current research is trying to explain these mechanisms of the impact of the disease progress on the level of individual patients. Due to the multidisciplinary nature such mechanisms can be viewed as an integration of social science research addressing psychological and social reaction to the disease process. Interestingly, empirical findings of elevated psychological distress was found to be just moderately related to conventional clinical measures [10,11]. This further implies that important causal influences may lie outside of the specific domain of the health status as it is traditionally defined by the physician. These findings are in line with other studies attributing relative weights of biomedical and psychosocial factors in the assessment of global well-being [3]. However, it still remains debatable as to what extent psychological distress already exists among patients in the early stage of their disease and which predicting factors contribute to the etiology of the diminished HRQoL [7,8].

Further, the symptoms of RA and psychological aspects may cause problems in many areas of life and often are a source of great burden to the patient. These effects may for example reduce or restrict one's ability to perform roles in the family, maintain various social roles, maintain work position or work performance at the same level, lead to the loss of valued activities and overall negatively affect the quality of social life and family life [12,13].

To summarize, within the research of Rheumatoid Arthritis a great emphasis has been paid to psychological and social variables as important

agents contributing to the disease course regarding its severity and overall adjustment. The significance of the psychological and social variables has been emphasized especially by mortality studies where these variables were more powerful than clinical variables. Yet further research is needed to reveal how and to what extent social and psychological resources are relevant and effective in ameliorating the RA impact and furthermore whether they can be of use in targeting interventions.

1.3 Psychological distress

RA patients often report elevated levels of psychological distress [14]. Psychological distress is usually approached as a compound of anxiety and depression [4,15]. Much research has been dedicated to the measurement and utility of assessing psychological distress in rheumatology practice. For example Strating et al. [15] have created a measure combining subscales of depression and anxiety and others like Wolfe and Skevington created a new scale for measuring distress in rheumatology practice. Generally, both have shown a close association with pain, fatigue and functional disability [15,16].

Throughout the research into RA different scales have been utilized to study and frequently used to measure psychological distress as a single construct; furthermore it is very valuable for screening purposes in everyday practice and monitoring during rehabilitation. The measures of distress have usually been assessed as a combination of the anxiety and depression subscales of the GHQ-28 [15] or by a disease specific measure such as the Rheumatology distress index [16]. However, distinguishing the individual components of depression and anxiety may be necessary to address.

A considerable amount of research has been dedicated to the exploration of depression. The prevalence of depression in RA patients been shown to be as twice as high as in the healthy population [16,17]. Empirical studies have further revealed that depression in RA patients is related to physical disability, pain, fatigue caused by RA but the underlying mechanisms of these relationships are not yet sufficiently clear [14,16,17]. Further it seems that disease-related variables alone are insufficient to fully account for depression [17,18]. While physical disability has been linked to depression it might not contain enough information about the specifics of an individual's social environment [19,20]. Associations between disease-related variables and depression have been analyzed further and Katz et al. for example have suggested a close connection between depressive feelings and the ability to perform valued activities claiming that it is not essentially the physical disability itself but rather very specific limitations imposed by it that may lead to depression [13]. This indicates that the extent of taking part in different activities within the social context might show a useful tool for understanding the relationship between the disease and depression.

However, it should also be noted that depression can be manifested by certain psychosomatic symptoms that might overlap with RA symptoms and thus provide biased information about the actual level of distress. Even after the correction for this methodological problem studies have found elevated

levels of psychological distress in patients with RA in comparison to healthy controls [21,22].

Much less research attention has been paid to anxiety, which is quite surprising as anxiety seems to be more prevalent than depression. Furthermore regarding care and counseling of RA patients it is very useful to distinguish between different aspects of psychological distress such as anxiety and depression as they are related but conceptually different. As for example Van Dyke et al. [23] found anxiety may be a risk factor for developing depression later and should not be overlooked.

1.4 Social and Personal Resources

Social and personal resources are very important although very difficult to comprehensively address and are represented by many different constructs in the current research. Within this thesis we will narrow our focus to two such coping resources: social support and coping self-efficacy.

1.4.1 Social support

Some studies have shown that a relatively close relationship exists between social support and psychological distress [24,25]. In particular specific approaches have been taken to examine this relationship and such approaches were applied in the context of chronic diseases following either the direct effect or the moderating buffering effect. Even though the existing findings are not fully conclusive both approaches have shown to be of great utility in the RA context.

A further important distinction regarding social support is that it can be addressed either as a structure reflecting one's rootedness in the social system or addressed at its functional level [15]. The functional level it is essential that the nature of the particular social support corresponds with the needs of the situation [15]. Effective management of RA requires external resources of social support as functional disability may affect the performance of daily activities to the level that lack of external assistance or instrumental support may become essential. A second relevant type of social support concerns the emotional needs and reactions of the environment. The disability occurs within a concrete social environment and thus how social support can be beneficial is closely connected to the availability of social support with respect the different types of social support and their specific functions [24,25].

Most studies addressing the problem of social support focus on the positive effects of interpersonal ties, whether in their structural or functional dimension [26]. In contrast, other authors argue that social support can be supportive and caring, but that it can also be characterized by misunderstanding, disapproval and antagonism [27]. Therefore it is very important that the approach also reflects the qualitative aspects of the provided support in addition to its function. This is underlined in studies reporting that satisfaction with social support is more closely related to

patient's well-being than the actual amount of supportive transactions [15,19]. To summarize it should be reiterated that social support to be an effective resource should correspond with an individual´s needs in respect to the amount of provided support as well as the required type. Within this thesis the focus is centered especially on two functional aspects of social support. These are instrumental support, and emotional sustenance defined as emotional support.

1.4.2 Coping self-efficacy

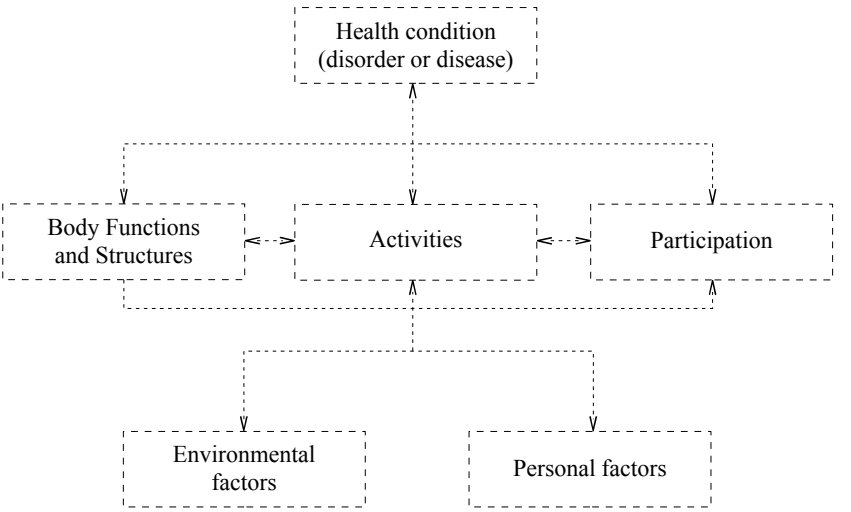
Coping can be defined as cognitive or behavioral efforts performed in order to manage stressful situations [28]. Research concerning specific coping strategies in the context of chronic diseases has shown high relevance regarding this construct [4,5]. More specifically it has been shown that the adaptation of coping can be both context and disease specific. Among RA patients it has been particularly shown that active coping strategies were more adaptive than passive strategies [29,30]. However, even active strategies might require too much effort to perform under the burden of long term chronic disease [4]. Moreover the unpredictable nature of RA may cause a decrease in self-efficacy whether it is related to very specific disease management activities or broader management of stress in different life situations [31]. In the RA context it might be especially important to maintain high self- efficacy as the disease progresses.

Self-efficacy represents a construct referring to the personal belief about one's ability to perform certain behavior successfully and with a desired outcome [5,31,32]. Research on self-efficacy in the RA context has mostly focused on aspects related to self-management activities such as beliefs about controlling pain, reducing fatigue, and managing restrictions imposed by disability [4,34]. Many studies have addressed the specifics of self-efficacy concerning symptom relief and self-management task [33,34]. Self-efficacy in relation to general coping behavior has been studied less even though it is highly relevant as it is occurring in the context of an ever present chronic stressor [5]. Moreover in the case of resignation to cope or depletion of one's personal resources for coping such as beliefs of self-efficacy, the long-term maintenance and psychological wellbeing are affected [4]. In particular not being prepared to prospectively cope with upcoming problems confronts patients with repeated stressors. These amounted stressors may cause considerable distress increased by RA and result into a vicious cycle connected with feelings of helplessness and maladaptive behaviors [8,9,17] On the other hand being self-efficacious and being able to maintain this belief about one´s coping abilities promotes adaptive coping responses especially during a longer period of chronic stress [18]. Within this thesis a relatively new construct of coping self-efficacy will be addressed.

1.5 Social participation

The scientific approach and research operationalization of disability and especially of the disability process has relatively recently undergone a significant shift by introducing the new model of International Classification of Functioning, Disability and Health (ICF) which has become a widely accepted classification system [1]. The ICF is based on an integration of medical and social models of disability and it constitutes a conceptual framework for understanding disability. The interdisciplinary view putting stronger emphasis on the interplay of biological and psychosocial factors seems to have prevailed in the current understanding of disability. Greater emphasis on the individual and the disability process has led to a new conceptual terminology which is also introduced in the ICF. Instead of putting the emphasis on limitations the attention is focused on resources and participation. The key terms of the model are impairment, activity and participation [1]. This is especially relevant for the diseases that are incurable and impose long lasting limitations.

Figure 1.1 Model of the International Classification of Functioning Disability and Health (ICF) [1]



The ICF thus provides an interactive model complementary to the social model that can be used more efficiently to address the issue of how environmental factors and personal factors might represent the key variables in studying disability. In particular the model suggests dynamic and reciprocal relationships among respective components of the model put within the context of personal and environmental factors. The ICF provides a useful framework for a multidisciplinary approach and is an important means for a common language in multidisciplinary research [1].

Participation is the key construct that has been included in the ICF to

replace the term handicap. Participation within this model has been defined broadly as involvement in life situations. This ICF model was created as an integration of two opposing models and those were a medical model and social model as previously mentioned. Within the medical model the central particle is the patient and his/her individual treatment which emphasizes the role of health professionals as the only experts healing a body part. Within the social model of disability social integration of an individual is emphasized and his/her active involvement is important. Social integration has been operationalized as social participation in different life situations which are represented by a whole spectrum of different domains such as social, economic, civic, interpersonal, domestic and educational. This shift in understanding and proposed approach to disability introduced by the ICF via the new model also coincides with the WHO view on health which stresses the importance of the context of the individual when assessing health and overall well-being [1].

On the other hand the concept of participation has also been criticized due to problems with clear definition of the related term within the model "activity". A relatively recent study which raised significant attention and became the most cited study of that journal introduced important points that should be taken into consideration [35]. Firstly, it is important that perspectives of people with disabilities are taken into account in the first place and that participation is assessed in reference to the social environment. The simple ability to perform different activities as such is not essential for participation but the failure to capture the subjective experience might be important [35].

Recent studies on factors associated with social participation in the general population include mainly variables such as older age, gender, basic mobility, balance confidence, activity level [36-39]. However the unique nature of individuals' conditions and subjective perception combined with equally unique differences regarding impairments, disabilities and especially diseases create significant difficulties in establishing a general approach.

Studies show that a variety of variables affecting social participation and disablement have to be understood as a complex process and its specificity must be taken into account across different contexts and different types of disabilities [35,36]. This is especially relevant for different chronic diseases which are incurable and may cause irreversible and lifelong changes in performing various activities and this way impose significant restrictions in participating in life situations.

Previously, the concept of quality of life (QoL) had been strongly supported and its utility especially advocated in the context of chronic diseases. According to the World Health Organization it can be defined as an individual's perception of his or her position in life in the context of culture and values system in which he or she lives and in relation to his or her expectations, goals and standards [1]. In the context of a chronic disease the personal evaluation of one's physical and psychological status is the focus.

Further, the concept of health-related quality of life (HRQoL) has been developed and applied in a number of studies [40,41,42]. HRQoL represents a concept derived from a broader concept of QoL narrowing its view to

issues related to one's disease. HRQoL has often served as a conceptual model relevant for addressing research questions in various areas of research and especially in the context of chronic diseases where disease usually imposes lifetime limitations. Although the conceptual distinction of HRQoL from the concept of QoL and its content has been a matter of scientific debate its utility is demonstrated in a number of studies [24,37,40].

A considerable interest in the application of this model has been seen in RA patients. The purpose of this is to provide useful outcome measures. This takes into account that the associations between physician-reports and self-reports have shown certain discrepancies. In particular typical symptoms of RA such as joint inflammation, deformities and progressive destruction of the joints lead to considerable functional decrease which eventually manifests as social disability [43,44].

1.6 Social and personal resources in RA

The onset and burden of RA brings about considerable changes in the patient's life [2,13]. As it is currently understood within the ICF model the impact of the chronic nature of RA is wide ranging and does not only affectt parts of the body but more or less the whole person in the context of his or her social life. RA itself might also bring about changes in the social environment through feedback from the social environment and these processes at the end inevitably affect the psychological status of the individual.

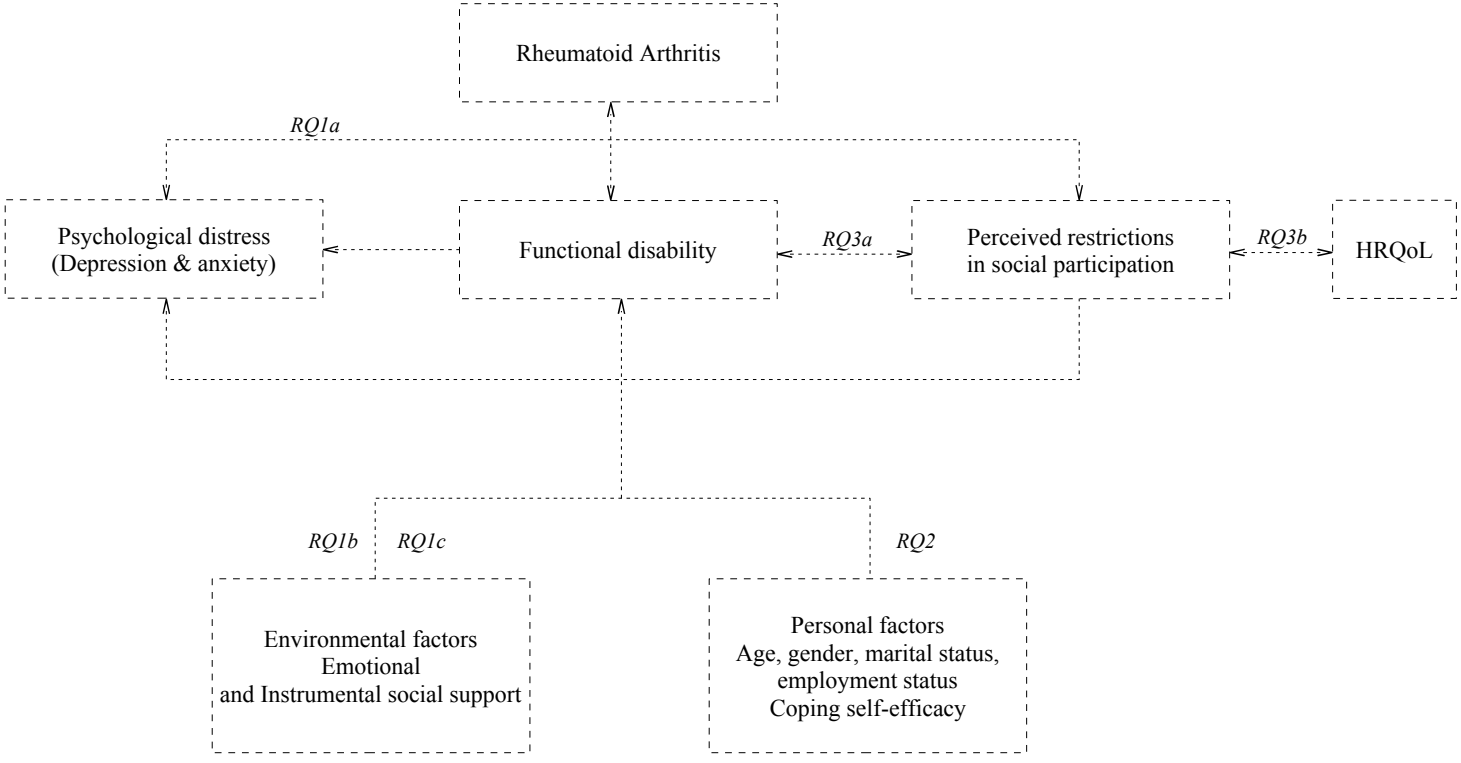
This thesis thus concentrates on the mentioned social resources (social support), personal resources (coping self-efficacy) and examines the benefits of involvement in social situations via social participation. These associations are studied longitudinally and cross-sectionally to capture and examine the role of social and personal resources at different periods of disease in RA patients.

1.7 Aims of the study

The research aims of the study lie within three main research topics and are depicted in Figure 1.2 within the ICF model.

The first objective was to investigate the pattern of the course of psychological distress, its associations with disease symptoms in RA patients within the period of four consecutive years with annual assessment points and explore the strength of its associations with joint tenderness, pain and functional disability as markers of disease activity over time. A further aim was to explore the role of social support in relation to psychological distress. In particular, emotional support and the instrumental types of support were addressed in order to explore how they can protect RA patients from experiencing depressive feelings. Specifically the goal is to examine whether emotional support and instrumental support can ameliorate the negative impact of RA via a moderating effect on the burden of the chronic nature of RA.

Figure 1.2 Interactions between the components of ICF model as studied in the thesis [1, 46]



The second main research interest focused on personal resources of the patients. In general, individual differences in personality and coping styles as well as specific self-efficacy have been addressed by previous studies in the RA context but the current aim focused on self-efficacy of patients regarding the use of their coping resources. It was theorized that coping self–efficacy would be negatively associated with depression and anxiety.

The third research topic of interest addresses social participation in RA. The final aim of the thesis was to explore whether differences among patients can be found in disease related variables and personal resources between patients who report different levels of restriction in social participation. The further aim was to explore the associations between social participation and HRQoL especially its physical and mental component.

Research questions:

Research question 1a: What is the course of psychological distress and how strongly is it associated with disease-related variables overtime?

Research question 1b: Are emotional and instrumental types of social support associated with psychological distress?

Research question 1c: Can emotional support and instrumental support ameliorate the negative impact of RA via a moderating effect?

Research question 2: Is coping self–efficacy negatively associated with psychological distress after controlling for relevant personality differences and disease related variables?

Research question 3a: Can differences be found in disease related variables such as pain, fatigue, functional disability and personal resources such as self-esteem and mastery between patients who report different levels of restriction regarding social participation?

Research question 3b: Are restrictions in social participation associated with health related quality of life?

1.8 Structure of the thesis

Chapter 1: The general introduction provides the basic background of the studied groups of rheumatoid arthritis patients and focuses on the importance of the personal and social resources in this chronic and incapacitating disease. Special attention is paid to psychological distress, social support and coping self-efficacy as important personal and social resources. Finally social participation as the crucial construct of the ICF model is introduced.

Chapter 2: Data sources are briefly described and general information about the studied samples and procedure is provided.

Chapter 3: Social support and psychological distress in rheumatoid arthritis are addressed especially in regard to the course of distress in early rheumatoid arthritis patients during four years. Further associations between emotional and instrumental types of social support and psychological distress are investigated longitudinally controlling for the erratic pattern of the disease activity.

Chapter 4: Social support as a moderator of functional disability´s effect on depressive feelings in early rheumatoid arthritis is addressed within this chapter. Social support is explored especially regarding its instrumental and emotional functions with respect to the possibility of the moderating effect on depression.

Chapter 5: Coping self–efficacy as an important personal resource is addressed in relation to psychological distress in cross-sectional data in early and established rheumatoid arthritis patients separately for anxiety and depression.

Chapter 6: Associations between social participation and disease related variables as well as personal resources in early and established rheumatoid arthritis patients are explored within a cross-sectional design.

Chapter 7: Associations between social participation and Health Related Quality of Life are investigated in early and established rheumatoid arthritis patients on cross-sectional data. These are explored especially regarding the mental and physical component of HRQoL.

Chapter 8: A general discussion of the findings is presented. The findings from the individual chapters are linked to the applied model and their implication is discussed on a more general level. Further strength and limitations of the studies presented in this thesis are discussed. Finally, implications of the findings within the specificity of the context are provided.

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